

Patient Stories and Evidence: A Complicated Relationship

FRANK GAVIN
CAHSPR CONFERENCE
MAY 10, 2016

Ground to Be Covered

- The Cascade of Patient Stories
- Lived Experience and Stories: The Artificiality of Stories
- Advocacy Stories: Their Uses and Limitations
- Patient Stories and Evidence
- Patient Stories as Evidence

Acknowledgement

My understanding of the function of stories has recently been enriched by reading Arthur Frank's *Letting Stories Breathe: A Socio-Narratology* (2010)

Thanks to Joanne Ganton for creating the best slide in this presentation and for allowing me to use it.

A Cascade of Patient Stories

Where do we find them?

- Newspapers
- Hospital and Health Charity Publications, including websites
- Patient Blogs
- Social Media—Blogs, Facebook, Twitter, Linked-In
- TV—News, Talk Shows, Ads, Dramas
- Movies
- Books

Lived Experience and Stories

- “Lived Experience”: Why the redundancy?
- Lived experience belongs entirely to the person / people who had it.
- It can be drawn upon without being converted into a story.
- Stories are creations / artifacts.
- Their beginnings, endings, and contents are selected and can be changed.
- They belong to their receivers (listeners or readers) as well as to their creators.
- Their meanings and implications are “open.”

More about Stories

Why do stories exist?

- To make sense of experience, the “this and then this and then this and then ...” of life.
- To explore roles and to help us discover and create identities
- To help us understand differences and borders and, sometimes, cross them.
- To “emplot” future possibilities
- To increase our sense of control over the unknown and the threatening

Where do stories come from?

- Experience
- Other stories

Advocacy Stories and Evidence

- Advocacy stories are shaped to achieve a particular purpose.
- Meaning and implications are—must be—clear and close-ended.
- Complications and perplexity are eschewed.
- Character types abound.
- If there are no sound tracks, they can be easily imagined.
- There are no unanswered questions and thus no or little need for new evidence.

Patient Stories and Evidence

- Patient stories—especially if they are allowed to move beyond the bounds of the anecdote—can help identify which questions most need to be answered, which situations / needs most need to be taken into account and examined:

“I can only answer the question ‘What am I to do?’ if I can answer the prior question ‘Of what story or stories do I find myself a part?’ – Alisdair MacIntyre, *After Virtue*

- Patient stories can provide insight into data and findings, highlight their implications, and identify their limitations.

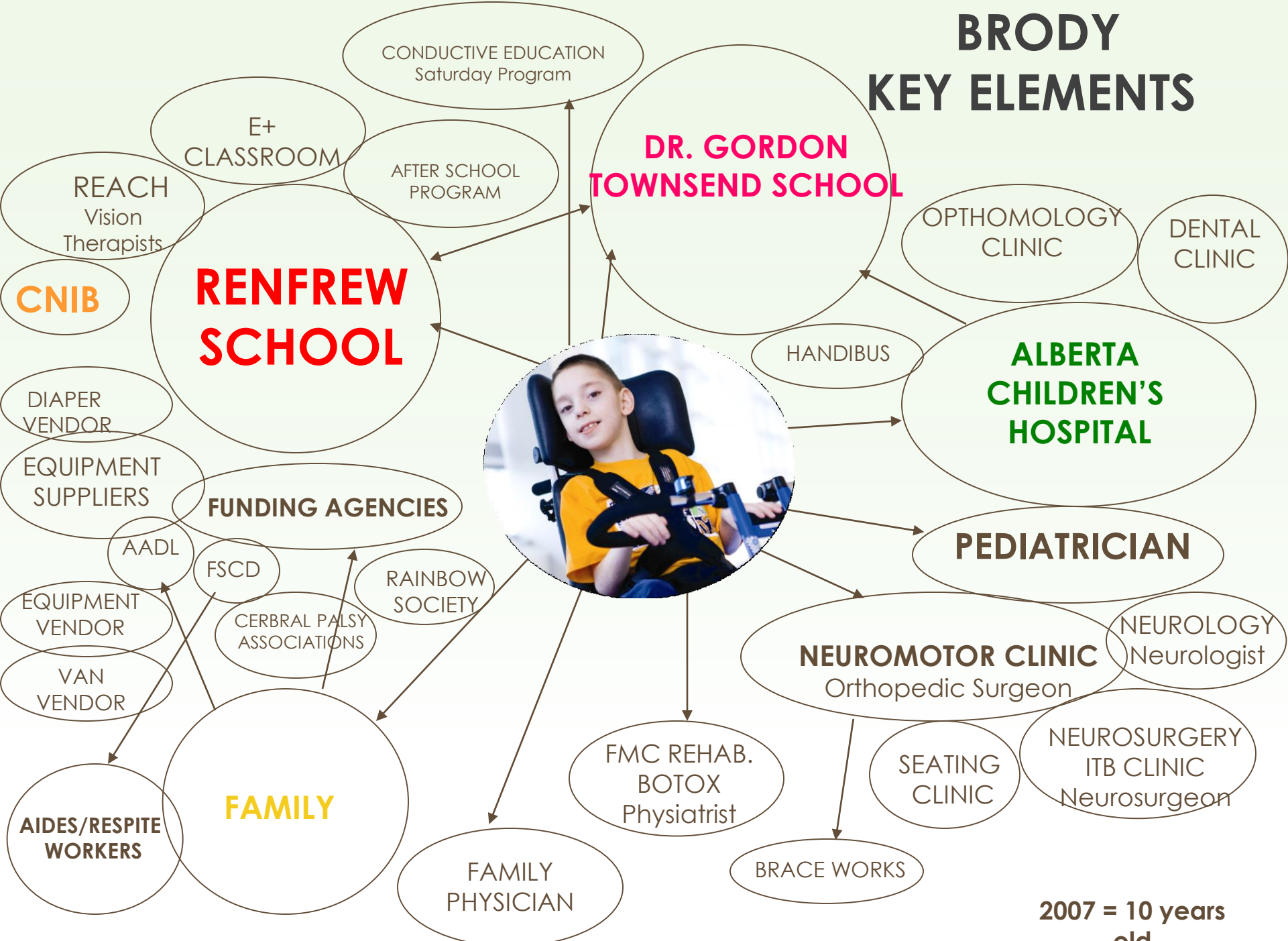
See Staley and Doherty, *Research Involvement and Engagement* (2016) 2:4 DOI 10.1186/s40900-016-0018-y (It's not evidence, it's insight: bringing patients' perspectives into health technology appraisal at NICE)

Patient Stories as Evidence

- Patient stories can offer the densest evidence when they grow out of and respond to life's complexities, its complicated truths, its paradoxes.
- Patient stories can offer evidence of how and why some things matter more than others to some and why small changes can make a great difference.
- Patient stories can offer evidence of what is possible now and in the future.
- “If we want this evidence, we need systems to support its quality and use” (Fiona Miller, University of Toronto)

Who hasn't discovered in a story convincing evidence of some truth that matters deeply?

BRODY KEY ELEMENTS



2007 = 10 years old